Department
of Health

Equality Analysis – The Public Sector Equality Duty and the Family Test

Infected blood: reform of financial and other support

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Target audience: Patients, in particular people affected by Human Immunodeficiency Virus (HIV) and/or hepatitis C through treatment with National Health Service (NHS)-supplied blood or blood products The current five infected blood payment support schemes, Macfarlane Trust, Eileen Trust and Caxton Foundation, MFET Ltd, and Skipton Fund Ltd. GPs Nurses Doctors Royal Colleges Social care providers General public
Contact details: Health Protection Emergency Preparedness and Health Protection Policy Directorate Department of Health Room 164 Richmond House 79 Whitehall London SW1A 2NS infectedbloodreform@dh.gsi.gov.uk

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Equality Analysis – The Public Sector Equality Duty and Family Test

Infected blood: reform of financial and other support

Prepared by

The Department of Health, England

Introduction

Context

This document accompanies, and is published alongside, the government response to our recent consultation on reform of financial and other support for people affected by Human Immunodeficiency Virus (HIV) and/or hepatitis C through treatment with National Health Service (NHS)-supplied blood or blood products: "*Infected blood: Government Response to Consultation on Reform of Financial and Other Support*"[1]. It covers how our consultation analysis and decisions for reform affect the groups protected under the government's Equality Act 2010 and through the application of the 'Family Test'.

The Public Sector Equality Duty

The general equality duty set out in the Equality Act 2010 requires public authorities, in the exercise of their functions, to have due regard to the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act.
- Advance equality of opportunity between people who share a protected characteristic and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.

The protected characteristics are: age, disability, gender reassignment, pregnancy & maternity, race, religion or belief, sex and sexual orientation.

The Family Test

In line with the Family Test (introduced in August 2014[2]), we also need to understand and consider the nature of any impacts on families, both positive and negative, by the proposals and decisions on reform of financial and other support for beneficiaries.

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[1] https://www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support

[2] https://www.gov.uk/government/publications/family-test-assessing-the-impact-of-policies-on-families

Equality analysis - The Public Sector Equality Duty and Family Test

Title: Infected blood: reform of financial and other support
Reform of the ex-gratia payment schemes for individuals infected with HIV and/or hepatitis C before 1991 through treatment with NHS-supplied blood and blood products

What are the intended outcomes of this work?

1.1 This equality analysis accompanies the government's response to the consultation on proposals to reform current payment schemes that government set up since 1988 for people infected with, or affected by, HIV and/or hepatitis C as a consequence of treatment with NHS-supplied blood or blood products. Over time the support system has become complex and has attracted criticisms from those it is intended to help. Our consultation on reform opened on 21 January 2016 and closed on 15 April 2016, having received 1,557 responses. The consultation sought views particularly from the beneficiaries of the current schemes, because they are the most impacted, and their clinicians. However, the consultation was open to all to respond.

1.2 This equality analysis provides an assessment of the government's package of reform following completion of the analysis of responses on the proposals set out in the consultation document. Primarily, this analysis looks at how any group of people with protected characteristics (see section 4 below) may be affected by the changes to current arrangements. An analysis of the 1,557 formal responses to the consultation and other feedback (such as a backbench debate on the issue, 21 Parliamentary Questions and 69 individual pieces of correspondence related to the consultation) informed the final key elements of the reformed scheme as set out in *"Infected blood: Government Response to Consultation on Reform of Financial and Other Support"*.

1.3 The government has listened carefully to the responses to its consultation. In deciding on the elements of the reformed scheme, we have taken full account of this feedback. We have also taken into account the need to ensure that the new scheme is equitable and transparent in terms of its future operation; that it makes the best use of available funding and that it remains affordable and sustainable over the lifetime of this spending review period (that is, until April 2021).

1.4 The package of reforms published in the accompanying government response is analysed in this equality analysis. The elements are:

a. **A single scheme administrator combining the functions of the existing schemes into a simpler scheme going forward**
b. **Increased annual payments for all infected who currently receive them, with Consumer Price Index (CPI) link maintained and including winter fuel payment**
c. **New flat rate annual payments for all those with hepatitis C stage 1 who do not currently receive them and, from 2017/18, the establishment of a new special appeals mechanism for hepatitis C stage 1s who consider they could qualify**

for stage 2 support

- **d. Retention of the £20k lump sum for those with hepatitis C newly joining the scheme (and similarly, retention of current HIV entry payments)**
- **e. Retention of the £50,000 lump sum for progression to hepatitis C stage 2**
- **f. Continuation of a discretionary scheme for infected and affected, as well as 'softer' support with an increased budget from 2018/19**
- **g. A one-off payment to bereaved spouses or partners of £10,000 in 2016/17. Newly bereaved partners/spouses will also receive a one-off payment of £10,000 when their partner dies (from 2016/17)**

Who will be affected?

2.1 Those primarily affected by these reforms will be infected individuals and family members of infected individuals, such as spouses or partners who have caring responsibilities, bereaved spouses or partners, and dependent children.

2.2 The existing staff of the five scheme bodies will also be affected by the reform to the scheme administrator.

Evidence

What evidence have you considered?

3.1 Evidence for this analysis was drawn from the following sources:

- The consultation document, *"Infected blood: reform of financial and other support",* the accompanying equality analysis and impact assessment documents that can be found at: https://www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support.
- Our analysis of the consultation responses conducted following receipt of all 1,557 electronic and paper responses between the period 21 January 2016 and 15 April, when the consultation was live, along with Parliamentary Questions, other associated correspondence sent, and a Parliamentary debate during this period. The responses to the consultation provided a rich source of information on the views of the beneficiaries of the scheme and other interested parties, our analysis of which is published in the accompanying document "*Infected blood: Government Response to Consultation on Reform of Financial and Other Support*".
- Annual reports of the three charitable bodies that operate current support schemes for infected people and family members (Macfarlane Trust www.macfarlane.org.uk, Eileen Trust and Caxton Foundation www.caxtonfoundation.org.uk), and those by two companies which provide financial assistance to infected people (The Skipton Fund www.skiptonfund.org, and MFET Ltd). The Eileen Trust does not have a website but can be contacted at: Alliance House, 12 Caxton Street, London, SW1H 0QS. MFET Ltd does not have a website, but information can be found at:

www.macfarlane.org.uk.

3.2 This analysis was also informed by:

- *"Review of the support available to Individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants",* published by the Department of Health in January 2011. This can be accessed at: https://www.gov.uk/government/publications/review-of-the-support-available-to individuals-infected-with-hepatitis-c-and-or-hiv-by-nhs-supplied-blood-transfusions-or-blood-products-and-their-dependants

- *"Inquiry into the current support for those affected by the contaminated blood scandal in the UK",* published by the All Party Parliamentary Group on Haemophilia and Contaminated Blood, January 2015, which can be accessed at: http://www.haemophilia.org.uk/what_we_do/influencing_advocacy/all_party_parliamentary_group

- "The Final Report of the Penrose Inquiry", published on 25 March 2015 at: http://www.penroseinquiry.org.uk/finalreport/

3.3 The consultation questionnaire contained 11 open questions about scheme reform. To ensure we captured the impact our proposals would have on individuals or groups of people affected by the reforms who are protected under the equalities legislation and Family Test, question 10 specifically asked "Are you aware of any evidence that would show our policy proposals would negatively impact any particular groups of individuals?". We also asked if respondents had any other comments they wanted to make regarding this (question 11).

The protected characteristics

Disability

4.1 HIV is considered a disability under the Equality Act 2010. Hepatitis C is not. Some people who have been treated may be disabled as a result of the treatment they received causing residual health problems or because of the severe impact of the infection. Additionally, some scheme members may be disabled as a result of other conditions.

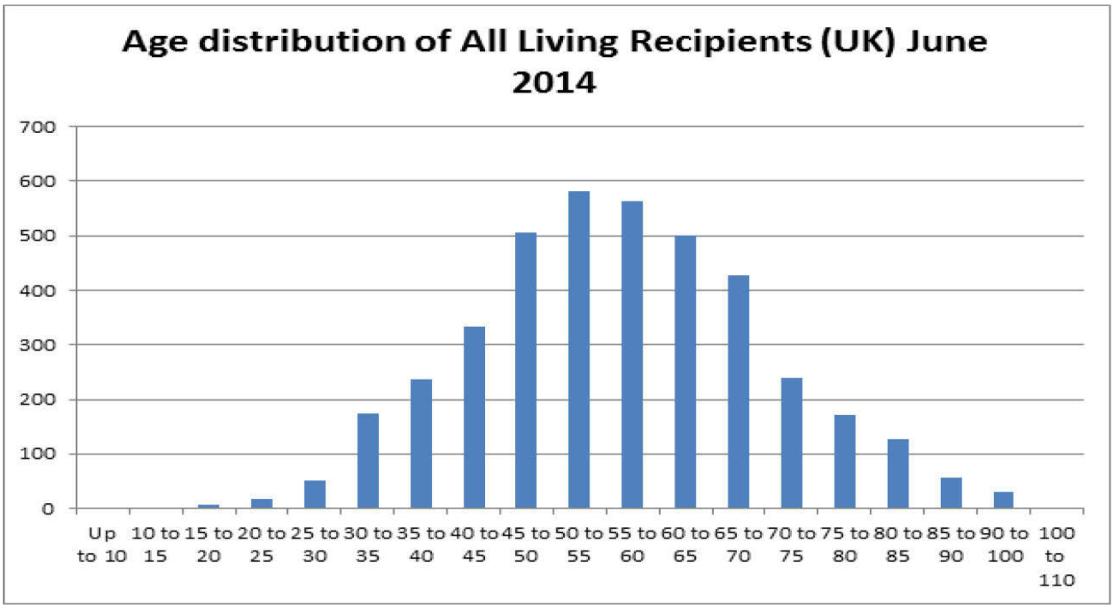
4.2 Under the present schemes, beneficiaries infected with HIV as a consequence of treatment with NHS-supplied blood or blood products automatically receive regular annual payments, as do some infected with hepatitis C, namely those at stage 2 of the infection (broadly speaking, those with cirrhosis). Those infected with hepatitis C at stage 1 do not receive an annual payment.

Sex

4.3 The biggest single patient group infected with HIV and/or hepatitis C through treatment with NHS-supplied blood or blood products are people with inherited bleeding disorders such as haemophilia, nearly 90% of who are male. As such, the majority of primary beneficiaries of the schemes are male, and the majority of bereaved spouses/partners are likely to be female.

Age

4.4 The overwhelming majority of individuals were infected before 1991, with the exception of a small number of people who were secondarily infected. The age profile of those living with infection in June 2014 is:



Gender reassignment (including transgender), Religion or Belief, and Sexual orientation

4.5 These protected characteristics are grouped because the bodies that operate the current payment schemes do not hold information on gender reassignment, religion or belief, and sexual orientation of claimants. We therefore do not hold information on current beneficiaries.

4.6 We received 1,557 responses to our consultation and none of the respondents provided us with any new evidence to say these groups would be particularly affected by our proposals for reforming the current payment schemes.

Race

4.7 Under the Equality Act 2010, race includes ethnic or national origins, colour or nationality. The bodies that operate the current payment schemes do not hold information on the racial background of their registrants. We are not aware of any particular race issues associated with the scheme beneficiaries, and the consultation responses provided us with no new evidence.

4.1 With regards to national origins, we know that those affected by the infected blood tragedy were infected across the UK. The consultation proposals and our response on scheme reform apply to only those infected through treatment in England (and the small number of people such as personnel from the armed forces who were infected abroad through their treatment with NHS-supplied blood products), and so this equality analysis is confined to an assessment of the impact on them.

Pregnancy and maternity

4.2 We do not have any information on pregnancy and maternity in relation to the affected community. There was no new evidence from the consultation responses regarding the impact of the proposed reform on women who share this protected characteristic.

Engagement and involvement

5.1 To help inform the consultation, we held engagement events with a small representative reference group of campaigners, with Members of Parliament from the All Party Parliamentary Group on Haemophilia and Contaminated Blood, and with the staff of the current schemes (details are given in the consultation document).

5.2 These events helped to inform our consultation and questionnaire therein, which contained 11 open questions about scheme reform, including a question on "Are you aware of any evidence that would show our policy proposals would negatively impact any particular groups of individuals?". Given the diversity of affected groups impacted by infected blood, and the fact that our engagement events and other evidence suggested a wide range of views across these groups about how best to reform aspects of the scheme, open questions provided the best way for all views to be expressed.

5.3 Our consultation sought to capture evidence from all stakeholders on those impacted by our proposals. We also invited their views on the evidence and equalities analysis, which we published alongside the consultation document.

5.4 This document provides our revised equality analysis – updated on account of the 1,557 responses we received and in line with our decisions about reform.

Summary of Analysis

6.1 In our consultation proposals and equality analysis we considered the potential impact on those infected individuals who are disabled, and proposed that those not already in receipt of annual payments would undergo an individual assessment and would receive annual payments based on those assessments (principally those with hepatitis C stage 1). We proposed the introduction of individual assessments to determine an amount of a new annual payment; the highest level was proposed to be the same as those with hepatitis C stage 2.

6.1 However, we have heard that the majority of respondents did not like the proposal of individual assessments. We also noted concerns that many disabled people already go through various forms of assessment for government support so subjecting them to another assessment was considered not be fair (see Chapter Two in the accompanying consultation response).

6.2 Thus, we decided not to proceed with individual assessments but to address any possible difference in treatment through the combination of the following two measures:

- With effect of April 2016, new flat-rate annual payments for all those infected with hepatitis C stage 1 in recognition of their chronic infection. This will benefit nearly 75% of all current beneficiaries (approximately 2,500 hepatitis C stage 1 beneficiaries).
- We recognise that there can be a wide spectrum of ill-health associated with chronic hepatitis C infection, some of which may be prolonged and severe, and also that the older treatments for hepatitis C infection can occasionally have a long-term health impact. While there was a clear message from the responses against individual assessments, some cases may only be determined on an individual basis. We will therefore introduce a special appeals mechanism for people currently at stage 1 to apply for a higher level of payment, equivalent to the stage 2 payments (that is, the stage 2 annual payment and one-off £50,000 payment for progression to stage 2). Applications to this special appeals mechanism will be voluntary.

6.3 This ensures that our payment scheme is responsive to individuals' needs and health status and that support goes to those whose health is most affected and therefore may be disabled as a result of their infection.

Detailed Analysis

Eliminate discrimination, harassment and victimisation, advance equality of opportunity between people who share a protected characteristic and foster good relations between those who share a protected characteristic and those who do not.

7.1 This section takes each of the seven aspects of the package of reforms in paragraph 1.4 in turn, and considers any potential equality issues related to each along with mitigating actions we considered.

7.2 It looks at our reform through the lenses of disability, age, and gender, where appropriate. Regarding the other protected characteristics of gender reassignment, race, religion or belief, sexual orientation; or pregnancy and maternity, these are not considered in detail as we hold no specific information about beneficiaries in relation to these characteristics. Furthermore, there was no new evidence from the consultation responses regarding the impact of the proposed reforms on these groups. We do not foresee any negative impact from our decisions on reform specific to any of these groups because beneficiaries would not be treated differently on the basis of any of these characteristics.

a) A single scheme administrator combining the functions of the existing schemes into a simple scheme going forward

7.3 We are now working towards setting up a single body to deliver the elements of the reformed scheme fairly and consistently to all scheme beneficiaries including those with protected characteristics. The single scheme administrator will provide all annual and lump-sum payments, and other support described below; and will aim to ensure equality of opportunity for all scheme beneficiaries.

7.4 As the functions of the five existing schemes transfer into the new scheme administrator, we will work with the current schemes and seek to ensure that during transition existing staff will be treated fairly, with dignity and respect regardless of their personal characteristics in line with the relevant employment law and good practice.

b) Increased annual payments for all infected who currently receive them, with CPI link maintained and including winter fuel payment element

7.5 All those infected with HIV and/or hepatitis C stage 2 will continue to receive their annual payments at an increased rate (from £14,749 to £15,000 per year plus a further increase to £18,000 in 2018/19). Every beneficiary in this cohort will receive the same amount of annual payment regardless of their personal characteristics. Those who are co-infected will receive the annual payment for both infections.

7.6 Further, these annual payments will include an additional single £500 winter fuel payment element with effect from this year. This removes the need for beneficiaries to apply separately for winter fuel payments from the discretionary schemes (as is a requirement now), which we appreciate has added unnecessary burden to beneficiaries, for example those in old age or with disability who may be particularly reliant on the winter fuel payment. As the payment is now automatically included in the annual payment, this frees up the equivalent budget in the discretionary scheme (described below) for additional support for those most in need.

7.7 We have heard concerns that future payments would not be linked to the Consumer Price Index (CPI). Many respondents noted that this would mean that over time they would be financially worse off, and that it could have a particular negative impact over time on the youngest scheme beneficiaries. To mitigate against these potential impacts, annual payments will continue to be linked to the CPI from 2017/18 onwards.

7.8 We know that a significant proportion of this cohort is disabled. Given that payments to all those in this cohort will be increased, we do not consider there to be a negative impact from this new payment scheme on beneficiaries who are disabled.

7.9 With regards to age, we know that over 60% of current infected scheme beneficiaries are over 60 years old (see point 4.4). Our reform to the annual payment regime will not differentiate on the basis of age – all those with HIV and/or hepatitis C stage 2 will receive the same payment. As the majority of those who will receive the increased annual payments are older beneficiaries, we consider this group may particularly benefit from the automatic inclusion of the winter fuel payment, while the continued link to CPI may particularly benefit younger beneficiaries (points we have also heard through the consultation responses). Overall, we do not consider that there would be a negative impact from our annual payment scheme on beneficiaries based on age.

7.10 On gender, we know that the majority of infected individuals is male. The reformed annual payment scheme will not differentiate on the basis of gender. Thus, we do not anticipate a negative impact from the reformed annual payments on the basis of gender.

c) New flat rate annual payments for all those with hepatitis C stage 1 who do not currently receive them and the establishment of a new special appeals mechanism for hepatitis C stage 1s who consider they could qualify for stage 2 support (from ‘17/18)

7.11 Currently those with hepatitis C stage 1 do not receive an annual payment - one of the biggest sources of criticism in the current schemes. Our reform addresses this by introducing new annual payments for all those infected with hepatitis C stage 1 in recognition of their chronic infection (£3,500 in 2016/17 and 2017/18, rising to £4,500 per year in 2018/19; all figures include winter fuel payment element and will be linked to CPI from 2017/18). This will benefit nearly 75% of all current beneficiaries (approximately 2,500 hepatitis C stage 1 beneficiaries). This may help to build good relations between beneficiaries who currently receive annual payments and those who do not receive annual payments.

7.12 We understand that there can be a wide spectrum of ill-health associated with chronic hepatitis C infection, some of which may be prolonged and severe, and also that the older treatments for hepatitis C infection can occasionally have a long-term health impact. We want to ensure those who experiencing greater ill health and who are more likely to be disabled as a result of their infection receive the same level of on-going support. To this end, we will introduce a special appeals mechanism for people currently at stage 1 to apply for a higher level of payment, equivalent to the stage 2 payments. This special appeals mechanism will be introduced in 2017/18.

7.13 Expert advice is now being sought on the criteria and process for the special appeals mechanism. Our criteria will be transparent and give clear, easy to understand guidance to those who may be eligible. The process will be mindful of the circumstances of beneficiaries including those who are disabled.

7.14 We consider that the special appeals mechanism is likely to help promote equality between all those in the scheme who are disabled.

7.15 The new hepatitis stage 1 payment scheme will not differentiate beneficiaries on the basis of gender or age. We do not anticipate any negative impact for any group on the basis of their gender or age (or as mentioned above on the basis of any of the other remaining characteristics).

d) **Retention of the £20k lump sum for those with hepatitis C newly joining the scheme (and similarly, retention of current HIV entry payments)**; and

e) **Retention of the £50,000 lump sum for progression to hepatitis C stage 2**

7.16 Currently, every scheme beneficiary receives a £20k lump sum upon joining the scheme. When we asked whether we should retain the lump-sum payment for new entrants to the scheme, the majority of respondents (72%) thought that the reformed scheme should continue to provide a £20k payment for those entering the scheme. The reformed scheme will thus retain this lump sum for anyone who newly joins. We consider that this will help to maintain good relations between infected individuals who are currently registered with the schemes, and all those infected individuals who join the scheme in future - regardless of their personal characteristics or background.

7.17 We also consulted on whether we should retain the £50,000 progression payment for those with hepatitis C stage 1 who progress to stage 2. 53% of overall respondents and 58% of those who identified themselves as having hepatitis C (the group most affected by our proposal) wanted the £50,000 lump sum to be maintained. We have thus decided to retain the £50,000 one-off payment for those progressing to hepatitis C stage 2. This reflects our desire to support those whose health is most affected regardless of their personal characteristic or background.

7.18 We recognise that maintaining the £50,000 lump sum may not promote good relations between those with hepatitis C stage 1 and hepatitis C stage 2 because some of the stage 1 cohort (those who are more likely to be disabled) experience similar health impacts to those at stage 2. However, we intend for the special appeals mechanism to enable those at stage 1 whose health has been most affected by their infection – including those who are disabled as a result of their infection – to receive equivalent stage 2 payments, which will help promote good relations.

7.19 In conclusion, while there are positive and negative impacts we consider that maintaining the £50,000 lump sum for those with hepatitis C who progress to stage 2, along with the special appeals mechanism for those whose health is most affected, is a proportionate means to meet one of our fundamental principles of reform – namely, that it should focus available resource on those whose health is most affected.

f) **Continuation of a discretionary scheme for infected and affected, as well as ‘softer’ support with an increased budget from 2018/19**

7.20 The consultation sought views on whether we should limit the discretionary scheme going forward to cover travel and accommodation costs associated with infection. We heard that the majority of respondents appreciated the availability of wider discretionary support in addition to receiving regular payments and that this support should go beyond the provision of travel and accommodation costs.

7.21 We have thus decided that the current discretionary arrangements will continue as they stand for the remainder of the financial year 2016/17. From 2017/18, the current discretionary arrangements will be replaced with a new discretionary scheme with a set of criteria that applies to infected and affected as consistently and practicable as possible.

7.22 This new system of discretionary support will be equitable, transparent and consistent for beneficiaries. It will have robust criteria and provide help to those who need it most, and in a way that does not see them “beg cap in hand” – a message we have consistently heard. The enhanced scheme will continue to include elements of financial and non-financial support, and be mindful to any challenges faced by beneficiaries as a result of a protected characteristic.

g) A one-off payment to bereaved spouses or partners of £10,000 in 2016/17. Newly bereaved partners/spouses will also receive a one-off payment of £10,000 when their partner dies (from 2016/17)

7.23 The consultation sought views on support for bereaved partners/spouses such as a lump sum payment and/or support from a discretionary scheme. The vast majority of those who responded considered that there should be a choice of support, and some noted that women would be particularly affected by our proposals for reforms to support for the bereaved. We have also received letters describing the positive effect discretionary support has on families and we have heard from Members of Parliament who have expressed concerns on behalf of their bereaved constituents.

7.24 In going forward, all those who are bereaved will continue to have access to support from the existing discretionary schemes and the enhanced discretionary scheme from 2017/18.

7.25 In addition, there will be a new one-off lump sum payment of £10,000 to all those newly bereaved who were the partner or spouse of a primary beneficiary when they passed away and where infection with HIV and/or hepatitis C contributed to the death of their partner/spouse. This will also apply to those already bereaved in 2016/17 which means that those already bereaved must claim their payment before March 2017.

7.26 We know the biggest single patient group infected are people with inherited bleeding disorders. Nearly 90% of this group are male. This means that the majority of bereaved spouses/partners who may qualify for the £10,000 payment are likely to be female – although our policy of course applies equally to any qualifying spouse/partner regardless of their gender (or any other protected characteristic). Our reformed scheme will increase the support available to this group by providing a lump sum in addition to discretionary support. Therefore we do not foresee there would be any negative impact from this policy on any group on the basis of gender.

The Family Test

7.27 In line with the Family Test (introduced in August 2014), we have considered the nature of any impacts on families, both positive and negative, of the package of reforms. The family test asks us to consider the following five questions:

1. What kinds of impact might the policy have on family formation?
2. What kind of impact will the policy have on families going through key transitions such as becoming parents, getting married, fostering or adopting, bereavement, redundancy, new caring responsibilities or the onset of a long-term health condition?
3. What impacts will the policy have on all family members' ability to play a full role in family life, including with respect to parenting and other caring responsibilities?
4. How does the policy impact families before, during and after couple separation?
5. How does the policy impact those families most at risk of deterioration of relationship quality and breakdown?

7.28 We recognise that bereavement causes significant emotional stress, and can also cause financial stress for families. We received letters describing the positive effect discretionary support has on families and we have heard from Members of Parliament who have expressed concerns on behalf of their bereaved constituents.

7.29 As described above, newly bereaved spouses/partners who were the partner or spouse of a primary beneficiary when they passed away and where infection with HIV and/or hepatitis C contributed to the death of their partner/spouse are offered a £10,000 lump sum payment. In addition, those bereaved, infected and affected continue to have access to the discretionary scheme now and going forward. The intention is that this support will provide relief during a difficult time for families. We therefore consider that the policy will have a positive impact on families going through key transitions such as bereavement and change to caring responsibility.

7.30 Only those bereaved spouses/partners who were the partner or spouse of the beneficiary when he/she passed away be will be eligible for the lump sum payment, meaning that this policy excludes former partners/spouses. This reflects our intention to provide support to partners or spouses of beneficiaries, within the financial envelope, in recognition of their relationship at time of death, where their partner/ spouse died as a result of their infection. Those who are no longer the spouse or the partner of the beneficiary no longer have that relationship status and are therefore excluded.

7.31 As we design the new enhanced discretionary support scheme, due consideration will be given to those currently relying on discretionary payments and to the elements of the existing schemes current beneficiaries find so valuable. The enhanced scheme will continue to include elements of financial and non-financial support.

7.32 In addition, as described above, all infected beneficiaries will receive increased and/or new annual payments, and of course they will also continue to have access to the discretionary scheme of financial and non-financial support.

7.33 In conclusion, we consider that our package of reforms is likely to impact positively on beneficiaries and their families.

For the record

Name of person who carried out this assessment: Rachel Devlin

Date assessment completed: 13 July 2016

Name of responsible Director/Director General: Helen Shirley-Quirk

Date assessment was signed: 22 July 2016